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Understanding the recovery process in psychosis

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KEYWORDS

Recovery, Psychosis, Qualitative Research

Abstract

Conceptualizing recovery in the context of severe and persisting mental health conditions is a complex issue. In recent years, there has been a call to re-focus research from understanding the *concept* of recovery to improving understanding of the *process* of recovery. There is a paucity of knowledge about the core processes involved in recovery from psychosis.

Objective: The authors aimed to gain insight into possible processes involved in recovery through analyzing data generated from a large qualitative study investigating employment barriers and support needs of people living with psychosis.

Research Design and Methods: Participants were 137 individuals drawn from six key stakeholder groups. Data obtained from focus groups (14) and individual interviews (34) were analyzed using thematic analysis.

Results: The main recovery processes identified were: learning effective coping strategies; recognizing personal potential; identifying and realizing personal goals; participation in social and occupational roles; positive risk-taking; and reclaiming personal identity.

Discussion: The results of this study have implications for treatment as well as the daily support needs of people recovering from psychosis.

Introduction

Understanding the process of recovery is inextricably linked to the dominant paradigm that exists for understanding mental distress. A radical paradigm shift has occurred in the last decade from a predominantly medical model that focuses on pathology, deficits,

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and ill health towards a more strength-based focus on recovery.¹ Although pharmacological treatments continue to be the mainstay of medical treatment, several non-clinical interventions have been found to be supportive. These include a range of self-management strategies including mindfulness, leisure, recreation, and exercise.²⁻⁶ Employment has also been found to be an important facilitator of clinical, personal, and social recovery.⁷⁻⁹

To date, the focus of recovery studies has been on understanding the *concept* of recovery in the context of psychosis. Recovery has been variously conceptualized in terms of clinical, social, personal, and functional outcomes.¹⁰ It has been suggested that, in order to progress the field, there is a need to move beyond consideration of conceptual issues to more of a focus on the *processes* involved in recovery.¹¹ Others have proposed recovery involved five recovery processes: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment.¹² Although purporting to describe recovery processes, their conceptual framework appears more accurately to describe key components or ingredients of recovery rather than the dynamic processes underlying recovery. Some researchers have proposed models of recovery from psychotic conditions that emphasize stages in recovery.¹³ Others, however, have contested the value of such formulations and argued that recovery is not a neat, linear process over time.^{11, 14} Therefore, much work remains to be done to clarify conceptual and process issues relating to recovery in psychosis.

Several authors have investigated factors affecting recovery in more severe mental health conditions. For example, one study found that stigma and discrimination negatively impact the process of recovery for people living with mental illness.¹⁵ A multinational qualitative study of twelve individuals with experience of recovery in psychosis identified common themes among participants' recovery experiences.¹⁶ These included how the person deals with the problems associated with psychosis, the role of material resources, the role of health systems, the role of significant others, and the role of social and cultural factors. A review of the literature highlighted the benefits of physical activity on mental health recovery.⁶ Another study affirmed the importance of participation in recreational activities for mental health recovery.³ The role of psychological factors in recovery has generally been overlooked.¹⁷ These authors argued that possessing insight into a mental health condition does not necessarily promote recovery, and that accepting a diagnosis and prognosis can in some circumstances constitute a barrier to recovery. They developed a model showing that hope and self-esteem, and overcoming self-stigma, are important factors mediating clinical and non-clinical outcomes. Importantly, these researchers found the general unpreparedness for the onset of psychosis, combined with loss of identity and lack of hope, can significantly delay the implementation of effective self-management strategies. It has been proposed that illness identity not only has an important impact on recovery but is also a possible area for psychotherapeutic intervention using approaches such as cognitive behaviour therapy and narrative therapy to change to a more positive identity.¹⁷ They cited evidence for facilitators of recovery among people living with psychosis including identity transformation-from negative self-identity to an

empowered self-identity; use of effective coping strategies, and participation in competitive employment.¹⁷

Qualitative studies appear to be well suited to study recovery in psychosis. Given that many researchers and clinicians perceive recovery in psychosis to be a uniquely personal process, in-depth case studies have potential to yield rich insights into the recovery process. For example, a narrative approach was used to investigate the recovery process in psychosis.¹⁴ Using semi-structured interviews and a narrative approach, the authors identified two divergent recovery typologies: turning toward and turning away. Turning toward involves normalization of voices, attempts to understand the meaning of voices in the context of one's life, and integration of voices into daily life. Turning away primarily involves distraction and reliance on medication. Relevantly, commonalities were found for both typologies in the recovery processes: acquiring general mental health skills; participation in meaningful activity; connecting with others; a changed response to voices; and developing a positive sense of self.¹⁴

The aim of the current study was to investigate the process of recovery in psychosis by searching data from a large qualitative study of people with lived experience of psychosis and of other key stakeholders associated with those with lived experience, to find statements or comments that might provide insights into the dynamic processes involved in recovery. Findings would have implications for interventions that might promote recovery among people living with psychosis.

Research Design and Methods

The data on which the current study is based was drawn from a large qualitative study of employment barriers and support needs in psychosis. The study involved 137 volunteer participants in South East Queensland who were invited to participate in focus groups (14) and individual interviews (34). To ensure a broad range of perspectives was captured in the study, participants were drawn from six key stakeholder groups: clients living with psychosis (25), care-givers (9), health professionals (19), employers (11), employment consultants (27), and community members (46). The sample included participants disclosing a wide range of ages (18-84 years), educational levels (primary school to tertiary level), and occupational categories. Ethical approval for this study was granted by Bond University Higher Research Ethics Committee, reference number RO1091. All participants were given a statement explaining the nature and purpose of the study and were required to provide informed written consent for their data to be used in the research. Focus groups and semi-structured individual interviews were conducted to elicit perceptions regarding barriers to employment and employment support needs of people living with psychosis. The researchers considered these methods would maximize the engagement of participants, facilitate disclosure, and allow the voices of vulnerable participants to be heard.

Focus groups comprising 3-10 participants drawn from the same stakeholder group were asked to respond to the following two main statements/questions:

- Question 1: We know that many people who have been diagnosed with schizophrenia or bipolar disorder would like to work in regular paid employment. We also know that the employment rate of people with these conditions is significantly lower than the general population. Why do you think this is the case?
- Question 2: What do you think would need to change in order to improve employment outcomes for people who have been diagnosed with schizophrenia or bipolar disorder?

Focus groups were of approximately one's hour duration, with approximately thirty minutes allocated to discussing each question.

In-depth individual interviews were conducted with participants who were unable to attend focus groups and/or whose life experiences were deemed, either by the researchers or by the participants in the study, as likely to provide a relevant source of data. Semi-structured interview schedules were developed which included the two main questions posed to focus group participants as well as a selection of open-ended questions tailored to the expertise and experience of the specific stakeholder group. A responsive interviewing style was used.¹⁸ In responsive interviewing, the interviewer listens deeply to interviewees and flexibly adapts the interview questions to elicit in-depth information and follow up on new insights. Interviews were of approximately one hour's duration and were recorded using two digital voice recorders. Recordings were transcribed verbatim and the transcripts were imported into NVivo 10 for analysis. The data were analyzed using thematic analysis, a qualitative analytic method.¹⁹ Another paper provided more information concerning the interview questions and procedures.²⁰

For purposes of the current study, all transcripts were thoroughly searched for all references pertaining to recovery from psychosis, and these were coded to a node labelled *recovery*. The contents of this node were subsequently reviewed and arranged into sub-nodes pertaining to the concept of recovery, recovery process, and barriers to recovery. Although references related to various aspects of recovery emerged from the data, only results on the process of recovery are presented in this paper.

Results

A thorough search of the transcripts revealed 106 references to recovery from 19 sources. Seventeen references obtained from 10 sources alluded to the process of recovery in psychosis. Recovery was conceptualized by participants in terms of a personal journey. For example, one client participant said:

"...it's actually a journey that you're going through now and stick with it, you know, persevere 'cause at the end of the day if you're just starting out...well I've had a pretty amazing life meeting the people I have for my mental illness."

The Process of Recovery

Participants perceived six key processes involved in recovery, namely, self-care, recognizing personal potential, personal aspirations, participation in social and occupational roles, positive risk-taking, and restoring personal identity:

Recovery is about self-care

This theme incorporated references to the role of self-management in facilitating recovery. Participants pointed to the need for individuals to be proactive in maintaining their own mental well-being. A client living with bipolar disorder emphasized the need to take personal responsibility for self-care:

"I know a lot of bipolar people would rather just sit there and say, 'Ah fuck it, it's the doctor's problem. They're the ones that made me this way.' Realistically no one's to blame but you *are* to blame if you don't get off your arse and help yourself...and you don't go see a doctor and try and sort out medication and if that doctor is not working for you shit go find another one, there's plenty out there and they're all there to help. It's taken me ten, fifteen years to find the right doctor...Now [that] I have I'm not letting them go!"

Recovery is about recognising personal potential

This theme captured references to looking beyond a person's mental health condition to recognize their unique human potential. A psychologist pointed out the importance of recognizing individual potential: "I think better assessment and multi-disciplinary assessment would be useful so that it's not a narrow view of illness but a broader view that brings more of the idea around potential that people have rather than the actual present condition because recovery is a lot about *potential*." Responses indicated that recovery is about identifying, claiming, and developing personal strengths. This view is reflected in the following client quotes: "...as long as I'm fit, I can pick up timber posts and that...with my hand you know... I'm pretty fit. If you put a bloke out on a property, on a station, there's farm work. You can pick up timber posts and there's good money in it..." "I'm still capable of working. You know there might be something wrong with my mind, but there's nothing wrong with my body...so I'm still capable of working..."

Recovery is about personal aspirations

This theme incorporated references to identifying and fulfilling personal goals and aspirations. Dreams and aspirations were deemed important to recovery. This perspective is illustrated in the following quote by a psychologist:

"Well it depends on what you're talking about when you say recovery. It's not necessarily a state that is very concrete, and

there *are* some people for whom going back to work is not realistic and for them recovery is more around them being able to live a fulfilling life in other ways...There are various contributions they can make. An obvious one is that they can be available as a companion or a friend of someone else with a mental illness like a buddy, support person. It really depends on the individual. They can be more active in their family. It really depends on what the person themselves (sic) considers to be a fulfilling life.... what *they* see as potentially meaningful and purposeful activity for their life."

Recovery is about participation in social and occupational roles

This theme comprized references to the importance of social and occupational roles in the recovery process. In addition to the pursuit of personal hobbies and interests, integration into socially valued roles such as study and employment were seen to be conducive to recovery. A carer commented, "I think there needs to be a whole different flexibility away from, you know, it has to be a job. It's really how do you get people to *flourish in, not just mental health, but in an interactive way...*".

Meaning in life was also identified as an important component of recovery. A client participant reported, "...by giving new members [of clubhouse] tours, it does give you a sense of purpose...gives you a sense of meaning to wake up." Importantly, meaningful activity was perceived to provide distraction from symptoms and alleviate boredom and social isolation which leads to rumination: A medical officer recalled, "I used to have a patient who ran their own [business] in xxx, did so for years, and you wouldn't know...she had voices most of the day, yeah, worse at night when she got home...because she wasn't distracted any more..." A psychiatrist affirmed, "...they will tell me, you know, doctor, when I work those voices are less. I get distracted from the voices, that's why I like my work." A client participant asserted "...the other thing that comes into play is the more time that I have by myself or the less interaction that I have with other people, the more I end up thinking about the past or thinking about things too much".

Recovery is about positive risk-taking

This theme incorporated references to measured risk-taking, which was seen as part of the recovery process. Measured risk-taking was seen to be part of the recovery process. An occupational therapist explained, "An important aspect of recovery involves challenging personal comfort zones. But not too much..." Participants questioned whether some health professionals and other key stakeholders provided sufficient encouragement for people to work and achieve their potential. Peer workers suggested that encouragement to take positive risks is necessary for recovery: "...it's just pushing them, you know, to take that risk and that's what recovery is about... just do an extra shift and see how you go and that they're capable of it but sometimes they don't have

that confidence." A client participant said: "I push myself to stay in there [work] 'cause / *know normalcy is what will make me better*, whereas a lot of other bipolar people will just go and hide under a rock and just say, 'Let's be done with it...I can't do this'..."

Recovery is about restoring personal identity

This theme incorporated references to the need to re-assert one's personal identity over an illness identity. Participants voiced the importance of understanding and insight into the relationship between their identity and their symptoms. A peer worker explained:

"The goal of recovery to me is to actually take that mental illness and what we say is put it on a leash (laughs) and put it in the background. It's in the background of your life rather than having it as your identity, which happens to a lot of people, that it's in the forefront of their mind, their lives, and it's like their whole identity is schizophrenia or bipolar. To me, recovery is when you make that smaller and smaller and smaller till....like honestly I forget about it, all the time, that I even had a mental illness...It's like it goes completely away and you're so busy living your life that you forget that you even have a mental illness".

A peer support worker pointed out the impact of social stigma on self-identity:

"With mental illness, they take the illness and make it the whole person. They don't usually do that with a physical illness. They don't usually take someone who's got some small physical illness that they're treated for and suddenly their whole life is about that [the illness] ...but the stigma makes people think that if you've got a mental illness that's all you are...."

In pursuit of socially recognized and valued roles, individuals gain and/or restructure a sense of personal identity. The process of building a sense of identity was illustrated in this client quote:

"...when someone [says to you] What do you do? [and you reply] 'I don't work' people really look down on you...but when you say I work at [retail food store] part-time...you're just like everyone else. You know you've got an identity or whatever it is."

Discussion

The aim of this study was to explore participants' perceptions of the process of recovery. A thematic analysis of the data revealed that the process of recovery involves at least six key processes: empowering self-care through developing coping strategies; recognizing personal potential; identifying and realizing personal aspirations;

participation in social and occupational roles; positive risk-taking; and restoring personal identity. There was support in this study for Leamy et al.'s view that recovery is a journey, and the framework for recovery they proposed which highlighted the importance of connectedness, hope and optimism about the future, identity, meaning in life, and empowerment.¹² Our study went further to suggest the importance of positive risk-taking in recovery. These insights have practical implications for the way in which individuals are supported on the recovery journey. It could also be argued that interventions to facilitate the six recovery processes identified in our study would promote recovery by generating connectedness, hope, self-identity, hope, and optimism.

Our finding of the importance of recognizing and realizing personal potential aligns well with the strengths-based approach.¹ In keeping with other studies that have emphasized the central importance of illness identity to recovery, our study found that establishment of a personal identity was an important recovery process.¹⁷ Positive sense of self has been identified as central to the recovery process.¹⁴ Our study extends this finding by spelling out how this might be achieved, for example, through overcoming self-stigmatization, recognition of personal potential, and support to develop and attain personal goals. Consistent with a study by Yanos et al., our study identified in the common themes of participants that learning effective coping strategies is an important aspect of the recovery process.¹⁷ This finding is consistent with De Jager et al., who found more specifically that a changed relationship to voices (that is, more effective coping) is an essential part of the recovery process.¹⁴ Similar to De Jager et al., who identified meaningful activity and connecting with others as an important recovery process, participants in our study highlighted the importance of participation in social and occupational roles in the recovery process. There was also evidence from our study to support the finding of Yanos et al. that participation in work can alleviate symptoms.¹⁷ Importantly our study highlights some other areas that have not received as much attention in the research literature e.g., the need for positive risk taking in what is essentially a risk-averse mental health system. This is a unique finding in this research and points to the need to challenge mental health systems that are typically risk-averse.

A limitation of this study is that the findings emerged from a study of employment barriers and support needs of people living with psychosis. Future studies, including case studies, that are more explicitly designed to elicit information about the key processes, barriers, and facilitators of recovery in psychosis would be helpful in progressing this important area of research.

The findings suggest that recovery outcomes for people living with psychosis may be facilitated through psycho-social interventions to support improved self-management, recognize and actualize personal potential, restore personal identity and manage the effects of stigma, and facilitate engagement in valued social and occupational roles. The findings suggest a need for more psychological interventions to promote recovery. These might include cognitive-behavioural therapies to improve self-management of symptoms;²¹ mindfulness interventions to enable people to develop a different

relationship with their symptoms;²² interventions to address self-identity issues and self-stigmatisation;²³ and interventions such as motivational interviewing to promote effective engagement of people with psychosis in valued social and occupational roles.²⁴ Furthermore, the findings on the importance of self-identity issues in recovery also suggest the need for broader social initiatives to reduce social stigma and discrimination, increase hope, and provide opportunities for social and vocational inclusion.^{10, 20}

Identifying the psychosocial processes underlying recovery from psychosis is an important area of research. This study identified six processes which were perceived by participants to be key in recovery from psychosis: self-care, identifying personal aspirations, recognizing personal potential, restoring self-identity, positive risk-taking, and participation in social and occupational roles. These findings have important implications for practice in the field of mental health recovery. Through identifying key processes, the study has improved understanding of the dynamic processes involved in recovery and pointed to several possible areas of psychosocial intervention, any one of which has potential to promote recovery of people living with psychosis.

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